Anthropomorphizing Atopy: Tweeting about Eczema[1]

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Atopic dermatitis or eczema affects a substantial minority of children and adults. Patients may treat their symptoms through skin care regimes and/or diet restrictions and/or prescribed topical corticosteroids. The patient perspective is important because of the long-term self-administered treatment regime and the potential psychological effects on relationships from a visible disease. This paper assesses the potential of public social media data to give new insights into patient perspectives through a thematic analysis of a random sample of 400 tweets from 2019 matching the query, "my eczema". Whilst the most common use of Twitter is to announce a flare-up, it is also used to express anger and discuss possible treatments. New themes not previously reported include the use of humor to discuss the condition and giving eczema agency: discussing it as if it had a will of its own. These may be defense strategies against the potential of eczema to strike at any time or the fear of negative reactions or blame from friends. This highlights importance of nurses and others helping patients to deal with the psychological effects of eczema.
Keywords: Atopic dermatitis; Eczema; Twitter; Social media; Patient perspectives.

Introduction

Atopic dermatitis or eczema is a complex skin condition that affects children and adults. It has varied clinical presentation but often causes itchy and dry skin with sore red patches, and typically varies in severity, including periods of remission. Whilst there is no cure, its symptoms can be treated with emollients or topical corticosteroids (Barfield, Brown, Pernell, & Woodard, 2017). As an allergic condition, those affected may gain relief by identifying and avoiding triggers or allergens. Eczema can be embarrassing when red patches are on visible parts of the skin and can be painful. The patient perspective is important for this condition because good skincare regimes are important for eczema management and symptoms may be distressing. In addition, adherence to recommended long-term emollient therapy regimes can be difficult, particularly for children (Santer, Burgess, Yardley, Ersser, Lewis-Jones, Muller, & Little, 2013).

The eczema patient perspective has been extensively analyzed through phone interviews with 48 adolescent and adult patients in the USA, producing a model of its symptoms and life burden (Grant, Larsen, Trennery, Silverberg, Abramovits, Simpson, & Bang, 2019). The main direct effects reported include itching, pain, and burning with red and dry skin, leading to indirect effects like discomfort and sleep disturbances. Patients also frequently reported embarrassment, anger, anxiety and other psychological impacts as well as restrictions to daily living and relationships. This creates a picture of a condition with extensive direct and indirect effects, reducing multiple quality of life dimensions.

Social media can be exploited to gain new insights into patient perspectives when they are free to comment rather than responding to questions in interviews, surveys or focus groups (Hilton, 2017; Sarker, Magge, & Sharma, 2017; Robinson, Turk, Jilka, & Cella, 2019). For example, blogs mentioning topical steroid withdrawal in children with atopic dermatitis have been systematically surveyed for insights, in the absence of directly relevant

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academic research (Juhász, Curley, Rasmussen, Malakouti, Silverberg, & Jacob, 2017). Other topics researched include tweets and Instagram posts about Mohs surgery (Kamath, Kursewicz, Ingrasci, Jacobs, Agarwal, & Nouri, 2019) and comments on YouTube dermatology treatment videos (Pithadia, Reynolds, Lee, & Wu, 2019).

Few previous studies have investigated patient reactions to eczema on social media. One short quantitative exception found beauty issues to be mentioned in 8% of Instagram posts with the hashtag #eczema (Yang, Beck, Sekhon, & Bhutani, 2018). In response, the aims of this study were to map how people discuss their eczema on Twitter and assess whether this could give new insights into the patient perspective.

Methods

Data

We used the quoted phrase queries “my dermatitis” and “my eczema” to identify tweets that were likely to be about the eczema of the tweeter. This is preferable to searching for the disease name alone, which matched marketing tweets in pilot testing. Social media is also used by dermatology advocacy groups and businesses (DeBord, Patel, Braun, & Dao Jr, 2019; Karimkhani, Connett, Boyers, Quest, & Dellavalle, 2014) and nurses (Schmitt & Lilly, 2012). In our estimation, the above phrase searches with 'My' largely eliminated the occurrence of tweets from professional organizations and health care providers. This strategy reduces the number of tweets gathered but enough were collected for the analysis, so this was not a problem. We submitted the queries to the Twitter API using the social media analytics software Mozdeh every 15 minutes from 13 August 2019 to 11 November 2019. We deleted duplicate queries, leaving 7811 from 6675 different tweeters for “my eczema” and 226 tweets for “my dermatitis”. Since the dermatitis query returned few results, we retained only the “my eczema” tweets for analysis to give a linguistically coherent sample. We used a random number generator to randomize the order of the tweets for analysis and the investigation terminated after coding 400 tweets, when we judged that concept saturation had been achieved.

Analysis

We investigated the randomly sorted tweets using the thematic analysis approach (Braun & Clarke, 2006, 2013). This method is suitable for health-related topics of relevance to practitioners because its results are more accessible than those from more theory-based qualitative approaches (Braun & Clarke, 2014). It is appropriate for this study since the analysis does not have an underpinning theory and the tweets are not part of a coherent discussion that would need a discussion-specific method.

First, we read the first 200 tweets twice and drew up a set of preliminary codes for relevant recurring features of the tweets relating to eczema. We then annotated the tweets with one or more of these codes, extending and modifying the codes as appropriate, and stopping after 400 tweets when saturation was achieved. We then rechecked the annotations separately for each code, with additional modification of some codes and some annotation changes. A second coder checked the codes, made corrections, and suggested changes. One area of disagreement was whether tweets should be marked as reporting pain implicitly from statements that the eczema was bad or had got worse; the final results only coded tweets for pain if they contained an explicit statement of pain. The other main area of

disagreement was whether eczema reported as "acting up" should be coded as giving agency to the condition; this was reported separately instead.

We grouped the codes into themes and subthemes. We then compared these, changing some themes, and moving some subthemes between themes. Finally, we chose names and examples for each theme.

Only public texts were used in this study, so it was exempt from ethical approval. All quotes reported in this paper were anonymized so that the owners cannot be traced by searching for their tweets.

Eczema tweets findings

This section reports percentages of tweets matching each theme as an indicator of prevalence (Table 1). The queries used may affect the relative prevalence of the themes, however. In particular, the requirement for tweets to contain "my eczema" is likely to ensure that they information is more personal than typical for Twitter.

- ***It's starting on my face.*** Almost half of the tweets mentioned eczema **symptoms** (178; 45%). A third of the tweets mentioned generally that the eczema had got worse or had (re)appeared, and a substantial minority specified *where* (16%) it occurred. This was usually the face, including the eyelids, or hands. Tweeters rarely explicitly mentioned that the face was the socially most awkward place to have eczema, but this is a likely reason for mentioning it rather than the insides of elbows (0 tweets) or the backs of knees (1 tweet). Other symptoms, such as *pain* (3%) and *itchy skin* (3%) were rarely mentioned.
- ***It flares up when the seasons change.*** A variety of potential or actual **triggers** were discussed (105; 26%), with the most common being **temperature**-related (54; 14%), such as heat, cold and weather changes. *Seasonal variations* in eczema were sometimes discussed (6%), often anticipating a longer-term worsening of the condition. Other common triggers discussed include *food* (6%) and *stress or anxiety* (4%). Triggers were discussed as known (usually temperature) or hypothesized.
- ***Using coconut oil now.*** **Treatments** (79; 20%) were suggested or commented on as ideas or known to be effective. The most common treatment was some form of *cream, lotion or ointment* (12%), usually not one prescribed by a health professional. Most tweets classified as spam were promoting a cream and these were ignored for coding. Another "treatment" was avoiding known triggers (6%, e.g., "having a dairy-free month – see if it works"). Few tweets mentioned consulting with, or following the advice of, a *doctor, nurse or dermatologist* (4%).
- ***Want to cry, hate my face.*** A substantial minority of tweets gave **emotional reactions** (89; 22%) to disease-related events. The most common was *anger* (11%), whether expressed through swearing (e.g., "my eczema is going fucken crazy") or by expressed as hate for the disease or symptoms (e.g., "I hate it"). The second most common was *sadness* (5%), through terms like crying, depressed, upset and fed-up. A few commented on a flare-up being particularly *bad timing* (2%, e.g., "the day before the interview, really???") and a few expressed relief at *symptom disappearance* (3%).
- ***It's not a hickey, I have eczema.*** A few tweets commented on **others' reactions** (20; 5%) to the disease, including directly negative comments (1%), and unwelcome advice or assumptions (3%). The scarcity of tweets *apprehensive about others'*

potential reactions (3%), including as expressed through insecurity presumably underestimates the scope of this issue.

- ***'Cold' by James Blunt triggers my eczema*. Jokes** (33; 8%) about *eczema severity* (5%) or *possible causes/treatments* (4%) were used to report eczema changes humorously (e.g., a cartoon horror gif) or as witticisms about potential triggers/cures.
- ***My eczema is furious at me in this heat*.** A substantial minority of tweets **anthropomorphized** (50; 13%) eczema, or at least attributed agency to it, usually as a humorous way to announce an actual or potential flare-up. An additional 5% reported eczema "act[ing] up" (or equivalent) but this standard metaphor was not included in the anthropomorphized 13%.
- ***This cream cured my eczema http://....*** A few tweets **advertised** eczema products (12; 3%), such as creams.

Table 1. Themes identified in 400 "My eczema" tweets. A single tweet may contain multiple themes or none.

Theme	**Tweets**
Symptoms	178 (45%)
Triggers	105 (26%)
Emotional reactions	89 (22%)
Treatments	79 (20%)
Anthropomorphizing eczema	50 (13%)
Jokes	33 (8%)
Others' reactions to eczema	20 (5%)
Advertising eczema products	12 (3%)

Discussion

The results partly echo previous knowledge about the patient perspective but also provide new insights. This section focuses on points not included in the recent conceptual model of the adult and adolescent eczema patient experience (Grant, Larsen, Trennery, Silverberg, Abramovits, Simpson, & Bang, 2019).

Eczema **triggers** are part of the patient experience as an explanation for their symptoms. Triggers are a natural topic on social media because of the fast-moving nature of tweets as status updates. Discussions of triggers may be introduced as an explanation to friends about appearance changes (perhaps to reduce the chance of a negative reaction when subsequently meeting) or as emotional venting at an out of control influence on their lives. The few tweets commenting on the bad timing of an attack (perhaps caused by stress) may also be related to this. The triggers themselves do not seem to be of interest because there are too few for a systematic survey of causes and there was no evidence of temporal trends in the tweeting volume.

Jokes about eczema are common. The prevalence of jokes about illnesses has previously been noted for mental health issues (Robinson, Turk, Jilka, & Cella, 2019), and as a coping strategy in a study of people living with chronic illness in Denmark (Sygeplejersken, Hovedstaden, Midtjylland, Nordjylland, Sjælland, & Syddanmark, 2006). Humor can be a defense against anxiety (Martin & Ford, 2018), perhaps about the condition or about revealing the condition to others. Tweets can find an audience for a humorous remark,

which gives it the important social context. The prevalence of jokes therefore underlines the severity of the psychological impact of eczema.

Anthropomorphizing eczema or giving it agency can be a form of humor and/or emphasizing that the disease is out of the control of the patient. Taken together with tweets about triggers and a few tweets mentioning unwelcome advice, this suggests that patients may need others to understand that their changed appearance is not their fault and so they should not be blamed. Anthropomorphizing or personification of diseases does not seem to have been analyzed empirically before, although one article has proposed that it may be used in response to chronic physical illness to express powerlessness (Shahar & Lerman, 2013). The use of the phrase "acting up" by patients to express worsening symptoms has been mentioned in passing in previous studies (e.g., de Waal, 2007; Nadal, Wong, Issa, Meterko, Leon, & Wideman, 2011) but does not seem to have been remarked upon as a noteworthy formulation.

Finally, patients rarely tweet to ask for help with their condition: only one tweet explicitly asked for advice. The function of Twitter seems to be for status updates and perhaps indirectly seeking social support rather than for discovering treatments.

Strengths and limitations

The strengths of this study include the use of non-solicited social media data to gain insights into aspects of the dermatology patient experience from a novel perspective, and that the method is straightforward to replicate. The limitations include the data only representing English-tweeting users of Twitter that are willing to discuss their condition online. The phrase searches used are also a limitation because other types of issues may be expressed using different language.

Conclusions

Patients seem to mainly use Twitter to announce symptoms, causes, treatments and reactions to them. This may be part of a management strategy to warn friends of appearance changes. Humor seems to be widely used as a reaction to the stress of an uncontrolled condition and perhaps also to emphasize that they should not be blamed or evaluated negatively for their suddenly changed appearance. Thus, nurses need to be sympathetic to the social stresses experienced by patients, particularly when concerned about the possible negative reactions of friends. Patients may benefit from nurses asking them how they are coping emotionally and suggesting strategies for managing reactions to their changed appearance, when relevant. Nurses may also need to help patients guard against feelings of powerlessness, as expressed by anthropomorphizing eczema, given the apparent importance of the psychological impacts of eczema. For example, highlighting the longer-term prospects for improvement if treatment is continued might return a degree control to patients.

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